

# e+bulletin

Epilepsy Toronto's publication of community news and events



The Purple Walk for Epilepsy

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## Comings and Goings at Epilepsy Toronto

*Epilepsy Toronto would like to welcome 2 new members of our staff team. Here are a few words from them.*

### Carter Hammett, Co-ordinator, Employment Services

My name is Carter and I'm the Co-ordinator of Employment Services. During my time here I've found myself deeply moved by the inspiring stories I've heard: stories of courage, resilience and hope. Often those stories centre upon the struggle to maintain a livelihood while dealing with the challenges of epilepsy and its related conditions.

With over two decades' worth of experience in social work, employment counselling, journalism and adult education across a broad range of sectors, I am also a graduate of Cape Breton University with a degree in Community Studies.

I'm here to help you plot strategies around issues like disclosure, self-advocacy and accommodations. If you need help with career planning, resume writing, interview skills or job maintenance issues, than I'm your "go-to" guy for those things as well. Together we can identify realistic career goals and the methods of accomplishing those goals.

I look forward to meeting and working with you!



### Jesse Preston, Job Developer

My name is Jesse, Epilepsy Toronto's Job Developer. Over the course of my life, I have been inspired to support the personal and societal development of people with disabilities.

My job involves connecting clients to opportunities for professional growth, assisting with the transition to employment and outreaching to employers to increase accessibility. Mock interviews, marketing, job search skills, networking, job coaching, advocating to employers and training are some of the many ways I can augment your job search.

A graduate in Business and Project Management from Centennial College, I have over five years' experience in recruitment, job development and coaching. During the course of my career, I have also been involved in the development of seven companies, programs and social projects, including the successful launch of the Athletic and Wellness Centre at Centennial and the CAN-tastic Food Bank project.

I'm happy to be working with and supporting Epilepsy Toronto's members.



## Twenty-20s

In October Epilepsy Toronto hosted a weekend meeting of the Twenty-20s Epilepsy Awareness Group. The initiative was created in July 2014, after twenty young adults with and affected by epilepsy from Canada, Jamaica, Puerto Rico and the US gathered in Washington, D.C. to participate in the inaugural North American “Young Adult Epilepsy Summit” organized by the North America International Bureau for Epilepsy (IBE) the Epilepsy Foundation of America Inc, Epilepsy Toronto and the Epilepsy Support Centre.

This weekend provided an opportunity for group members to reconnect and discuss ideas about how to move their goal of raising public awareness about epilepsy forward and how to promote Purple Day in their home communities. They also told their stories on camera; the videos will be released as part of the Twenty-20s social media activities.



## Thanks

Thanks to Irene Elliott for her many years of service on Epilepsy Toronto’s Board of Directors. Irene’s expertise as a former Pediatric Nurse Practitioner at the Hospital for Sick Children has been an invaluable asset to our agency.

Irene stepped down from the Board of Directors this fall but continues to be a dedicated member of our volunteer team.



Irene Elliot with ET President Daryl Yeo

## epilepsy@work

The epilepsy@work toolkit, developed by Epilepsy Toronto with funding from the Accessibility Directorate of Ontario, is online and ready for use.

We are looking for businesses and organizations interested in becoming more accessible or creating a supportive environment for people living with epilepsy. If you know an organization that might benefit or being interested in using this resource, email [info@epilepsyatwork.com](mailto:info@epilepsyatwork.com).

## Lifelong friendships built at Camp 'Cooch'

*For over 60 years, boys and girls aged 6 - 16 have enjoyed residential summer camp experiences at Camp Couchiching. Often referred to as Camp Cooch, the camp is known for one of the most exciting camping experiences to be found in Ontario.*

*The camp integrates children and youth with epilepsy into the camp experience with as much or as little support as necessary. Most importantly, it's a chance for kids living with epilepsy to be kids.*

*Recently, Epilepsy Toronto client Tobin Kravchenko told his story about life at Camp Cooch to the Toronto Star.*

By: Leslie Ferenc, Toronto Star, reprinted with permission.

LONGFORD MILLS, ONT.—It can be tough being away from home and some kids do get a touch of homesickness while at camp.

It's part of the rite of passage.

The ailment isn't long lasting at Camp Couchiching where there's so much to do with old friends and new that thoughts of home roll off like water from a duck's back.



Tobin at Camp Couchiching

Tobin Kravchenko, 12, will confirm that. He's been coming to "Cooch" as camp is affectionately known, since he was six and knows his way around. It's a fantastic way to spend a couple of weeks in the summer.

"The counsellors are really nice and interact with everyone," he says. "There are so many activities too. I like swimming, canoeing, kayaking and basket ball. I also like hanging out with friends."

He also likes the fact that campers get to choose what they want to do and that no one is judged.

"Nothing is complicated at camp," he says.

At the moment, his pals have climbed up onto the water trampoline just off the shore, bouncing into the air before hurling themselves into the water. It's a hoot and holler and their screams and laughter tell it all. Tobin can't wait to join them and flexes his water trampoline muscles.

But first, more about his experiences at Cooch where he says the food is awesome, especially the great brunch at the end of each week which is a real treat. His meal usually consists of Fruit Loops, bacon,

eggs, milk and a croissant. "It's like being in a hotel," he says with a laugh.

Then again, growing, active boys like Tobin need their nutrients for energy to keep up with all the activities.

While having a great time is the ultimate achievement, Cooch is where kids learn many practical and life skills without even knowing it, such as respect and consideration. Sailing is something he hasn't quite mastered. "I fell over (tipped) a few times and got back up," he says. "It was okay."

Football on the other hand was a real blast and he's looking forward to playing more.

"I've also learned how to co-operate with others better," says Tobin. It comes from teamwork that's an important aspect of camp. "I'm not shy anymore and have made a lot of good friends."

So what makes good camp friends?

Tobin has the answer at his fingertips. "They comfort you when you're having a hard time and are a lot of fun. At Cooch, you meet new people who turn into friends."

It's why he suggested that a friend of his come and see all that Cooch has to offer. "My friend was really scared he'd be away from his parents for a long time," says Tobin. "I told him he wouldn't remember his parents because he would be having so much fun at camp. He came for a weekend this summer to see what it was like and he loved it."

Having been there and done it, that friend is coming back.

## Camp Cooch

Summer 2016 registration for Camp Couchiching opens in December.

Epilepsy Ontario also helps sponsor children living with epilepsy to attend Camp Cooch as part of its Summerfest program. Details can be found at [www.epilepsyontario.org](http://www.epilepsyontario.org).

For more information contact Katie Lundy, Director of Children and Youth Services ([katie@epilepsytoronto.org](mailto:katie@epilepsytoronto.org))

## See the Person Videos

In August, Epilepsy Toronto released two new videos of our members telling their stories.

Guided by our commitment to 'See the Person', the videos show the range of impacts that epilepsy can have on the lives of people living with seizures and their families. They also give a glimpse into what our agency does to support Toronto's epilepsy community.

Epilepsy Toronto is indebted to the Downtown Yonge Business Improvement Area, one of our BuskerFest supporters, for funding the videos and shining a light on our members and our agency's work.



You can view the videos on our website [www.epilepsytoronto.org](http://www.epilepsytoronto.org).

## Medical Marijuana Forum

In October Epilepsy Toronto and EpLink co-hosted an information session about medical marijuana and seizures. It brought together physicians, researchers, and parents to share their perspectives and experiences with using marijuana for seizure control.

Moderated by Mark McAllister, the panel included McIntyre Burnham discussing the current state of research into medical marijuana and seizures, Dr. Bláthnaid McCoy from Sick Kids Hospital sharing a physician's perspective, and Andy Ayotte and Alexander Repetski sharing their experiences as parents and advocates.

More importantly, the room was packed with family members and people living with epilepsy. They were there because they desperately wanted to share their experiences or find out if medical marijuana might be an option that would make an impact on their lives.

Questions and comments ranged from issues of proper dosages, side effects and safety concerns, to when to consider marijuana as an option or alternative treatment. Two themes emerged throughout the discussion: patients and parents desperate to find a safe, effective way of controlling seizures are willing to look at medical marijuana as an option; and there is a deep desire from patients, researchers, and physicians for more research into when that option can be safe and effective.

Andy Ayotte, whose adult daughter Stephanie was having multiple daily seizures and side effects from medication she was taking, reflected on the decision to look into medical marijuana "You get to a point; 'what on earth do you do'". Since then there has been a significant reduction in the number of seizures Stephanie is having.



Dr. Bláthnaid McCoy

Dr. McCoy stressed the desire for better research so that physicians and patients are making informed decisions about medical marijuana use to treat intractable seizures.

"I know that a lot of us are working very hard to make this something we know and understand better," she said, noting that as a physician she has a raft of concerns including correct dosage, formulation and what forms of epilepsy are most treatable.

"I know that we can find the evidence, and that's what's missing," she said.

Epilepsy Toronto and EpLink have posted videos of the panel discussion available on our websites.

## Is Marijuana Right for Me? Questions & Considerations

Here is a list of questions you are encouraged to discuss with your physician and other service providers when considering the use of cannabidiol for the management of seizures:

- Should I consider the use of medical marijuana considering my seizure frequency and the proven therapies that are currently available?
- What are my physician's thoughts about the use of medical marijuana for seizure management?
- How do I get a medical certificate for the use of medical marijuana to control my seizures?
- If I am able to get an exemption, where can I get high quality medical marijuana?
- Which licensed producer is able to produce high-quality products? How do I know what product to buy? How should I take it?
- Can I take cannabidiol (CBD) without taking tetrahydrocannabidiol (THC)?
- What percentage of CBD or (THC), if any, should I take? Can I trust the Licensed Producer with the stated amount of CBD/THC in the oil?
- Can I use marijuana off the street and not a licenced dealer to help me manage my seizures?
- Will the use of medical marijuana interfere with the anti-seizure medications I am currently taking? Can additional tests be performed to ensure anti-seizure drug levels are not affected by the use of medical marijuana?
- How long should I be taking medical marijuana to determine if there is an effect?
- What side effects should I be looking for when taking medical marijuana?
- What precautions should I take when using medical marijuana?

## Toronto International BuskerFest

2015's edition of BuskerFest was an incredible event, bringing together performers, volunteers, sponsors and spectators, all in support of Epilepsy Toronto. Sadly, 2015 will be the last year Scotiabank will be sponsoring the festival. We want to thank Scotiabank and the many staff who helped make the festival such an amazing event and we hope we can find other ways to continue our partnership in the future.



# The Purple Walk for Epilepsy

The first ever Purple Walk for Epilepsy in Toronto was a huge success, raising over \$100,000 for our services.

In 2015 Epilepsy Toronto started our very own walk; a chance to walk in solidarity with others who care about epilepsy.

Why Purple? Purple has become widely accepted as the colour of epilepsy. It's bright, bold and a perfect colour to celebrate epilepsy.

With breakfast provided by our friends at Red Line Coffee, purple face painting, balloon twisting (from the balloon artists, the Twisted Ones) and a fun celebration before the walk, the march was lead by epilepsy ambassador Tristan Thompson and ended with a special concert at Dundas Square.

Thank you to everyone who helped make this event possible!

